



Spring 2011

THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



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ING New York City Marathon

November 6th 2011—If you are interested in running & raising money for the IBD Center, contact Tom Fitzsimmons at ChildrenIBD@mssm.edu

Future Lecture & IBDKids Chat

group: October 11th and December 13th 2011

Staying Positive with UC

By Erik

I never let UC ever control my life or slow me down. I was a very active person playing a lot of ice hockey and always outside mountain biking or having paintball matches with my friends. I was always doing something physical. My parents knew there was something wrong with me just by watching me during my sophomore season of varsity high school hockey as they noticed my game was off and I was slower and looked as if I was out of shape. I had a colonoscopy and was diagnosed with UC in February of 2006, a month before my 16th birthday, right after finding blood in my stool a few days prior.

Soon after being diagnosed with UC I was hospitalized for over a week. While I was in the hospital I met a lot of wonderful and very helpful staff while at Mount Sinai, including Dr Benkov and his office staff. Months went by and I was treated with medications that most people with UC were given but they did not help control my symptoms. The only medication that was helping me was a steroid called prednisone. As months went on I gained about 50 to 60 pounds due to the prednisone. Even though the steroids changed the way I looked, I never let it slow me down. I had to stop playing hockey. This affected me a lot, hockey was my life! I had been playing since I was 8. I continued to be active and still went mountain biking as much as I could.

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Children's IBD Center Evaluates Complimentary & Alternative Medicine

By Kathy Hoffstadter-Thal, NP

In March 2009, the Children's IBD Center in collaboration with Dr. Xiu-Min Li, professor of pediatrics and the Director of the Center for Chinese Herbal Therapy and Department of Pediatric Allergy and Immunology at Mount Sinai, began a study looking to see if a Chinese herbal formula developed by Dr. Li, has an effect on the blood and colon (large intestine) cells of children who have Crohn's disease. These cells were studied in the laboratory with the Chinese herbal formula with the thought that if the formula works on the cells, it may have potential as an alternative or complimentary treatment for Crohn's disease. Before any medication can be tested in humans, whether alternative, complimentary or traditional, scientists must be able to prove that it has a desired effect and is safe. This information is obtained through laboratory experiments. To date, we have received samples from 102 subjects who have participated in the research study and we look forward to presenting the data as soon as it is available.

With this laboratory study and the apparent willingness of families to participate in mind, Clare Ceballos, NP, Clinical Coordinator at the Children's IBD Center, decided to apply for a grant to investigate family's attitudes towards the use of complementary and alternative

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Researching Anxiety and IBD

By Alexis Briggie, M.A., and
Laura Reigada, Ph.D.

Anxiety disorders are common and can be disabling. For children with IBD, these disorders take on particular significance given that they are already trying to cope with a medical condition that can be challenging. Furthermore, stress can exacerbate symptoms of IBD and anxiety disorders can disrupt interpersonal and school related activities, which may already be compromised by having to manage a medical condition.

Some degree of worry is a completely normal part of life. At times, worrying can even be helpful—it can motivate us to do things, like study for an important test, or protect us in dangerous situations by making us more alert. While a certain amount of anxiety or concern in children and teens is normal, when fears become overwhelming and hard to control, or limit your child's ability to enjoy certain activities, it may be helpful for your child or teen to talk to someone about their fears.

For kids with inflammatory bowel disease and for their parents, anxiety can be particularly hard to identify. One of the reasons for this is because many of the “warning signs” that are typically associated with anxiety in youth are *physical* symptoms, such as fatigue, stomachaches, nausea, diarrhea, and headaches—many of the very same symptoms that are caused by inflammatory bowel disease. Therefore, it can oftentimes be very difficult for you or your child to figure out whether a particular physical symptom is caused by illness, anxiety, or both.

Dr. Laura Reigada, a clinical psychologist, has teamed up with Dr. Keith Benkov, chief of the division of Pediatric Gastroenterology at Mount Sinai School of Medicine, and his research team to help youth with IBD manage their worries. If your child is between the ages of 8 and 17 and has a diagnosis of Crohn's disease or ulcerative colitis, they may be eligible

to participate in a 13-week, no cost treatment program aimed at coping with IBD and reducing anxiety. If you are interested in participating or learning more about this project, please contact Dr. Laura Reigada at [718-951-5000](tel:718-951-5000) (ext. 6021) or via email at lreigada@brooklyn.cuny.edu.

Staying Positive with UC

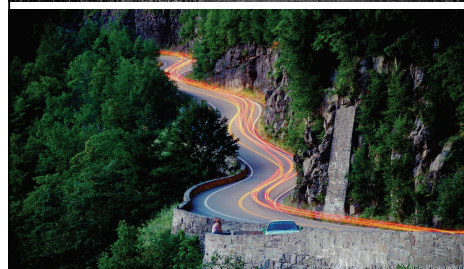
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Eleven months went by and no medications were helping to put me in remission. I continued to be steroid dependent and it was recommended by Dr Benkov to have my colon removed and to go through with this surgery as soon as possible because I needed to be taken off the steroids. Two weeks later I met my wonderful surgeon, Dr Harris. His plans were that I would have to go through two surgeries three months apart from each other to remove my colon. The first surgery was February of 2007. Dr Harris removed my whole large intestine with the exception of my rectum and I was given an ileostomy. The first week or so after that surgery was tough but I got used to having an ileostomy and just thought positive because I knew that the worst was behind me. I wasn't sick anymore and I was no longer suffering from the cramps and pains of UC. I returned back to school after my 6 weeks of recovery and I planned on passing my junior year of high school! Three months came and went quickly, it was time for my second surgery. During this surgery Dr Harris would remove the remainder of my rectum and I would no longer have an ileostomy. He made a J - Pouch out of my small intestine which would be my new rectum.

I have come a long way since 2006 when I was first diagnosed with UC. I missed over 21 weeks of my Junior year of high school but with home tutoring I passed the school year. I returned to playing hockey my senior year and it was such a wonderful feeling to be playing again. I am 21 now and have taken up photography and just started up with my own

business. I am also working for a European car website. I attend multiple car shows and events all over the east coast to cover the event and promote the website. I have met so many wonderful people and have made many friends.

I never allowed UC to run and control my life. All I can say is continue to do your best and never give up!



A selection of Erik's photographs

Complementary & Alternative Medicine Research at the IBD Center

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medicine for themselves and for their children with IBD. Through a grant awarded by the Center for Nursing Research & Education, at the Mount Sinai School of Medicine, Clare began a survey study. The survey was initially sent by e-mail and 160 families responded. This anonymous survey takes about 5 minutes to complete and is presently being given out to parents of children being seen at the Children's IBD Center.

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The Children's IBD Center strives to advance our knowledge of IBD and IBD treatments through research, to provide our children with the safest and most effective therapies to promote wellness.

We appreciate those families who have helped us in our research endeavors. If you would like to find out more about these studies please talk to your physician or ask for a survey at your next visit.

A Penny Harvest for the IBD Center

By Nanci Pittman, MD

This spring, a dozen students from PS 42 came to visit The Mount Sinai Hospital.

These students are a select group of 4th and 5th graders who are part of the Round Table group at PS 42. The group focuses on community service and philanthropy. At a young age, they are exposed to the importance of charity and helping others. They run a collection called "Penny Harvest" through which they collect and then donate \$1,000 dollars to the organization they choose. Each year they research a



Students from PS 42 learning about IBD at Mount Sinai

few charity organizations. They learn about the organization, what the organization does and how their contribution might be helpful. This year, they chose to learn about IBD and the IBD Center. While at the hospital, we met in the Zone and discussed IBD. We spoke about the features of IBD and how it affects the life of a child. The students had many questions that were both insightful and thoughtful. We were thrilled to have them visit with us; it was a great morning.

Farewell to Dr. Tomaino



Congratulations to Juli Tomaino, MD who completes her fellowship in pediatric gastroenterology in June. Dr. Tomaino will be taking a position at Children's Memorial Hospital in Chicago this summer.

Making the Transition from Home to College

By Tali

When I finished my senior year of high school I was extremely excited. I had decided on the school I wanted to go to (Skidmore College). The excitement of registering for

classes, filling out rooming questionnaires, shopping for my dorm room, and countless other preparatory steps, was overwhelming. At the same time, I was anxious about leaving home where I relied on my parents so much to remind me to take my medicine, to be there for me when I wasn't feeling well, and to be a consistent support system.

The first day of college was emotional in many ways; it was overwhelming to see so many new faces, it was sad to say goodbye to my dog (okay, and my parents and brother too), and it was intriguing and thrilling to meet so many new people. I was also scared about going from a high school where all of my friends knew I had Crohn's disease, to a college where I would be alone once again.

To get my mind off the hard parts of this drastic life change, I jumped right in. At the club fair I signed up for a few new things that I'd never tried before (like Japanese traditional drumming club), I auditioned for the orchestra and a few quartets, I found a mentee in the town to tutor, and got myself interested in the subject matter of my classes. I was busy from the get go and didn't have much time to think about home or Crohn's.

Getting involved helped me occupy my time and meet lots of people, of all ages, not just freshman. It's been great to have the advice of upper-classmen to seek when I need it, and I've met all my upper-classmen friends through an extracurricular of some sort. I talked to my parents and friends from home every day at first so that I could tell them everything before I knew who I could trust completely here at Skidmore. It was good to be able to talk everything through, because with so much changing it's hard to process it all.

Eventually, I opened up to my closest friends about having Crohn's, and they were all extremely impressed that I didn't make a big deal about it. Knowing now that my friends support me and know about this part of my life is extremely valuable for me. These friends helped make my transition from high school to college smoother.

CCFA Summer Camp August 16-21, 2011



The CCFA runs a co-ed residential summer camp for children living with Crohn's disease and ulcerative colitis. They are currently accepting applications for campers in grades 3-10; for the leaders in training program for grades 11-12; and for volunteers over age 18.

If you are interested in this fantastic experience contact the CCFA at www.cffa.org/camps.

Can You think of creative ways to support The Children's IBD Center? Targeted grant money, donations to our existing programs and your ideas and participation all help. Please contact us at childrenIBD@mssm.edu to discuss your ideas and help support our work.

We want your feedback regarding our programs and suggestions for improvements to better meet your needs. In the coming weeks, we will be sending a survey to families followed at The IBD Center via electronic mail. Please complete the survey, which takes about 10 minutes to fill out. It will help us to better serve the families who come to the Center. Thank you from The Children's IBD Center Staff.

We want to hear from you:

To contact us or to receive updated information about Center events, please contact us:

E-MAIL: childrenIBD@mssm.edu **Please email us so we may add you to our contact list and keep you updated on Center activities!**

PHONE: 212-241-5415

WEB SITE: www.IBDKids.org

The Children's IBD Center at Mount Sinai is funded in large part through philanthropy. Please contact us if you are interested in making a contribution to support our Center or in learning about other ways that you can help.

Resources for Families:

www.IBDKids.org

www.CCFA.org

www.medlineplus.gov

The Children's IBD Center at Mount Sinai offers the following services for families:

- **Regular lectures where you can learn more about the disease and meet other families & Center staff**
- **IBDChat, an interactive group for kids with IBD & their siblings**
- **IBD Parent Chat, A support group for parents by parents**
- **IBD Tuesdays, where you can see our Social Worker, Child Life Worker, Psychologist, Nurse Practitioner & Dietician in the Faculty Practice**
- **A website of resources for families www.IBDKids.org**



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